

**Challenges in disclosing and receiving a diagnosis of dementia: A systematic review of practice
from the perspectives of people with dementia, carers, and healthcare professionals**

Jennifer Yates¹, Miriam Stanyon¹, Rajvinder Samra², and Linda Clare³

¹Division of Psychiatry and Applied Psychology, School of Medicine, University of Nottingham

²School of Health, Wellbeing and Social Care, The Open University, Milton Keynes, MK7 6AA

³College of Medicine and Health, University of Exeter

Running head: Dementia diagnosis disclosure: A systematic review

Correspondence address:

Jennifer Yates
C22, Institute of Mental Health,
Jubilee Campus,
University of Nottingham,
NG7 2TU

Telephone: 0115 8230410

Email: jennifer.yates@nottingham.ac.uk

Word count: 6000

Author contributions: JY and MS conducted the systematic review and the quality analyses of the included articles. JY wrote the article and MS, RS and LC all contributed to writing the article. All authors designed the review.

Conflict of interests: None

Abstract

Background: Disclosing a diagnosis of dementia is a key process involving people with dementia, carers, and healthcare professionals (HCPs) that can facilitate access to treatment and support. Receiving a diagnosis of dementia may represent a change in identity and loss of a planned-for future, resulting in an emotional impact for both people with dementia and carers. Delivering the diagnosis of dementia can be difficult and draining for HCPs.

Methods: We conducted a systematic review that included studies which explored the experience of giving or receiving a diagnosis of dementia from the perspectives of people with dementia, carers, or HCPs. All study designs were eligible except for previous literature reviews. Findings were analysed thematically and grouped into categories, and then synthesised into a narrative review. The quality of all included studies was assessed.

Results: Fifty-two studies were included in this review. Findings indicated that receiving a diagnosis is generally a negative process for people with dementia, carers, and HCPs and leaves carers in particular feeling uncertain over the prognosis and future of the person they care for. Disclosing a diagnosis of dementia is a difficult and complex process, for which formal training and guidance is lacking. Carers in particular would welcome more opportunity for realistic and hopeful discussions of the implications of receiving a diagnosis of dementia.

Conclusions: Changes in some aspects of disclosure, such as providing a truthful diagnosis to the person with dementia, have occurred over the last decade. A process approach involving pre-diagnostic counselling and follow-up appointments could enable discussions regarding prognosis and the future, create opportunities to clarify the diagnosis, and reduce emotional burden on HCPs. There is a need for more objective evidence that considers the perspectives of all individuals involved.

Receiving a diagnosis of dementia is an important step for people with dementia because it facilitates access to interventions, and potential support from health and social services and third sector organisations (Robinson et al., 2015). Receiving a diagnosis may be an emotionally charged experience, representing a transition in identity for people with dementia and their carers requiring an emotional readjustment and reappraisal of their future (Robinson et al., 2011). The proportion of those developing symptoms of dementia who receive a diagnosis has increased in the UK (Abhayaratne et al., 2019) and internationally (World Health Organization., 2020), partly in response to policy changes (Department of Health, 2015), and due to greater awareness and acceptance of dementia. A recent systematic review (van den Dungen et al., 2014) using a pooled average based on 9,065 respondents from 23 studies demonstrated that approximately 85% of people with cognitive impairment would wish to be told a diagnosis if one were made. Knowledge of prognosis and illness trajectories enables people to plan and ensure their affairs are in order or undertake lifestyle changes (Woods et al., 2019). Typically, in developed countries, diagnosis disclosure occurs in secondary care settings, conducted by professionals such as psychiatrists, clinical psychologists, or specialist nurses. However, some diagnosis disclosures occur in primary care, delivered by a primary care physician. The time from developing awareness of cognitive changes to receiving a diagnosis varies across individuals, but can be a lengthy process; a delay of three years is not uncommon (Chrisp et al., 2011). The communication and delivery of the diagnosis requires careful management to account for a variety of reactions, needs and levels of understanding from both the person with dementia and carers accompanying them to the disclosure meeting (Bunn et al., 2012).

There are differences between HCPs' perceptions of best practice when disclosing a diagnosis of dementia and the perceptions of people with dementia or carers, which raises ethical dilemmas about how to respect these different needs (Dooley et al., 2015). An earlier literature review (Lecouturier et al., 2008) identified a list of best practice behaviours and combined this with a

qualitative exploration and consensus approach to identify eight categories of best practice for disclosure. These categories comprised preparing for disclosure, integrating family members, exploring the patient's perspectives, disclosing the diagnosis, responding to the patient's reactions, focusing on quality of life and well-being, planning for the future, and communicating effectively. Whilst comprehensive, this review is now over ten years old and the authors did not critically appraise the included research. Another review (Werner et al., 2013) covering a similar topic and time frame addressed a broad range of topics related to dementia diagnosis disclosure, but without a specific focus on which practices are typical and how they might be perceived. Given the recent policy initiatives around early diagnosis and changes in societal awareness of dementia over the last decade (Department of Health, 2015) an updated review of the evidence regarding disclosure from the perspectives of people with dementia, carers, and healthcare professionals (HCPs) is required.

Objectives

This review aimed to explore the experiences of giving or receiving a diagnosis of dementia. It identified common disclosure practices, challenges associated with disclosing the diagnosis, and needs of different individuals involved in the disclosure. It extended earlier work by including a systematic search strategy and a critical appraisal of the results using an established quality assessment tool, and went beyond describing the range of possible practices and behaviour to identify what is reported as typically occurring in practice and how this is perceived.

Methods

Search strategy

A search of the PubMed, CINAHL, and Web of Science databases was conducted on 31st October 2018; updated on 7th February 2020. Reference sections of included papers were hand-searched to

identify further publications. The terms 'dementia' AND 'diagnosi*' were used to search titles and abstracts. A second search was conducted which combined these with the terms 'disclosure' OR 'best practice', used to search in all fields. The study flowchart is shown in Figure 1. Due to the large number of studies conducted on this topic, the search was restricted to the last ten years (2008 onwards).

Study selection

Studies were included if they were written in English and provided information on delivering or receiving a diagnosis of dementia. All study types were eligible except for articles that only included a review of previous literature. Studies from the perspectives of HCPs, patients, and carers were all considered. The two primary reviewers (JY and MS) screened the titles, excluding articles that were not relevant, and then reviewed the abstracts. Full texts were retrieved if the title and abstract suggested that an aspect of delivering or receiving a diagnosis of dementia was explored. JY and MS conducted this task jointly, resolving differences in judgement through discussion and agreement.

Data collection and synthesis

Data were extracted using a table developed by JY and MS to capture the study details (Table 1). Initially, JY and MS extracted the data together to ensure consistency, before continuing to extract data independently and amalgamating tables once complete. As data were extracted, a number of similar ideas and issues were identified in the findings. These were collated in a separate document and added to by JY and MS until data extraction was complete. Similar findings were grouped to form thematic categories. These themes were refined and amalgamated where possible through discussion and during the writing of the narrative by the whole research team. Themes were reported in a narrative format.

Quality review

Methodological quality was assessed by JY and MS using the Joanna Briggs Institute checklists (Aromataris and Munn, 2017). The corresponding checklists for each study design were used. A rating of methodological quality that was comparable across different designs was made by calculating the number of items endorsed on each checklist for each article and converting this into a percentage. Ten percent of the articles were sampled using a random number generator and assessed for quality by a third reviewer (AH). Reviewer scores were compared for consistency using a paired samples t-test. No significant differences were found ($t(4)=2.33, p=.080$), suggesting a robust quality assessment.

Results

Fifty-two studies were included. Main findings are summarised in Table 1. Findings are categorised under the following themes: *content of the diagnosis disclosure; emotional impact; communication of the diagnosis; people involved; attitudes towards diagnosis disclosure; use of diagnostic tests and assessments; truth telling and deception; timeliness; and training and skills.*

((Figure 1 about here))

((Table 1 about here))

Quality assessment

Quality assessment scores are shown in Table 1. Detailed assessments can be obtained on request. The scores represent the percentage of items on each study design-specific checklist endorsed, and

higher percentages reflect higher quality. Scores ranged from 60% to 100%, and of the 52 studies, 13 scored 100%, seven scored 90-100%, 14 scored 80-90%, 12 scored 70-80%, and six scored 60-70%.

Studies scoring lower tended to have qualitative designs. The most frequent quality issues included a failure to specify the underpinning philosophy of the research approach, so the congruence between the philosophical perspective and the research methodology was unknown, and a lack of reflexivity to locate the researcher culturally and theoretically, acknowledging the impact of the researcher on the research and vice versa. Studies scoring higher tended to utilise survey designs, consensus methods, and observations.

Study design types

This review included one case report, 20 cross-sectional studies yielding quantitative data, five studies that were opinion pieces, commentaries, or utilised consensus methodologies with experts, 24 qualitative studies, two quasi-experimental studies, and one randomised controlled trial.

Participant characteristics

Participants were HCPs, people with dementia, carers, and people who had attended memory assessment services but not received a diagnosis of dementia at the time of participation. Sixteen studies included only the perspectives of HCPs, four studies included only the perspectives of people with dementia, one study included the perspectives of people without a diagnosis of dementia, and seven studies included only the perspectives of carers. Sample sizes ranged from two to 1409. The term 'carer' was used in most studies to refer to the individual accompanying the person receiving the diagnosis to the disclosure meeting. Other terms including 'relative' and 'companion' were also used (Table 1). For brevity, the term 'carer' is used in this review.

Setting

Studies were conducted in clinic and community settings, in the UK (Eccles et al., 2009, Bennett et al., 2018, Hillman, 2017, Innes et al., 2012, Manthorpe et al., 2013, Milby et al., 2017, Page et al., 2015, Peel, 2015, Samsi et al., 2014, Stokes et al., 2014, Vince et al., 2017, Lecouturier et al., 2008, Bailey et al., 2019, McCabe et al., 2019, Xanthopoulou et al., 2019), USA (Burns et al., 2017, Lim et al., 2016, Lingler et al., 2016, Connell et al., 2009, Carpenter et al., 2008, Campbell et al., 2008, Bradford et al., 2011, Grill et al., 2017, Grossberg et al., 2010, Sakai and Carpenter, 2011, Wynn and Carpenter, 2017, Zaleta and Carpenter, 2010, Zaleta et al., 2012, Champlin, 2020), China (Zou et al., 2017), The Netherlands (van Wijngaarden et al., 2018), Brazil (Shimizu et al., 2008, Raicher et al., 2008), Belgium (Segers, 2009, Mormont et al., 2012), Australia (Phillips et al., 2012, Mastwyk et al., 2014, Hansen et al., 2008), Denmark (Nielsen et al., 2018), Ireland (Moore and Cahill, 2013, Foley et al., 2017), Canada (Lee and Weston, 2011), Finland (Laakkonen et al., 2008), Israel (Karnieli-Miller et al., 2012), Germany (Kaduszkiewicz et al., 2008), Switzerland (Giezendanner et al., 2018), Japan (Abe et al., 2019), and Malta (Caruana-Pulpan and Scerri, 2014). Three studies used a pan-European design, involving several countries contributing to data collection (Porteri et al., 2010, Visser et al., 2012, Woods et al., 2019) and one study was international (Villars et al., 2010). The majority of studies were conducted in the UK (12 studies) and the USA (13 studies).

Themes

Content of the diagnosis disclosure

In a survey of specialist physicians in Denmark, most respondents reported that they always or often provided information on aetiology, progression, and causes of symptoms, and they tailored the information provided depending on the degree of cognitive impairment, specific type of dementia, and level of emotional distress (Nielsen et al., 2018). People with dementia and carers in other

studies reported receiving only basic information, and felt they lacked information (Samsi et al., 2014), or that nothing was explained (Innes et al., 2012). Messages conveyed should be positive and hopeful, whilst still being realistic (Vince et al., 2017, Phillips et al., 2012, Lee and Weston, 2011, Lecouturier et al., 2008, Grossberg et al., 2010). People with dementia and carers indicated that they wanted to know more about the future and prognosis (Lecouturier et al., 2008, Laakkonen et al., 2008, Grossberg et al., 2010, Lee and Weston, 2011), sources of support, and local community health and social services (Foley et al., 2017, Innes et al., 2012). The diagnosis disclosure should include information regarding well-being, such as how people with dementia can continue with life as much as possible, maintain their sense of self, and accept their identity as a person with dementia (Vince et al., 2017).

Carers in two studies reported being unsure what to ask in the disclosure meeting (Manthorpe et al., 2013, Laakkonen et al., 2008), and felt that approaching diagnosis in stages might be preferable to enable people with dementia and carers to absorb and process the information (Laakkonen et al., 2008, Lecouturier et al., 2008). However, in one study 55% of respondents reported preferring to receive the whole disclosure up-front (Mastwyk et al., 2014).

The diagnostic process should be structured to ascertain the beliefs, expectations, and potential misconceptions that people with dementia or carers might have. This might include determining what people with dementia already know about dementia (Lee and Weston, 2011), identifying patient-centred informational needs (Bennett et al., 2018) and may take place in pre-diagnostic counselling ahead of disclosure meetings (Lecouturier et al., 2008).

Emotional Impact

Eighteen studies explored the emotional impact of receiving a diagnosis of dementia. Studies reporting on the emotional impact of the diagnosis on people with dementia suggested they had experienced negative emotions (Zou et al., 2017, McCabe et al., 2019), including feelings of depression (Segers, 2009, Laakkonen et al., 2008), anxiety or nervousness (Segers, 2009, Mormont et al., 2012, Lim et al., 2016), shock (Samsi et al., 2014, Milby et al., 2017, Innes et al., 2012), loss (Samsi et al., 2014), grief (Samsi et al., 2014, Laakkonen et al., 2008), dejection (Samsi et al., 2014), sadness (Mormont et al., 2012), fear (Milby et al., 2017, Phillips et al., 2012), and shame (Kaduszkiewicz et al., 2008). One study reported that the diagnosis disclosure also brought satisfaction at receiving an explanation (Mormont et al., 2012). Three studies reported that some people with dementia were either indifferent upon receiving the diagnosis (Segers, 2009), had not experienced significant distress (Zaleta et al., 2012), or showed initial anxiety that was not sustained over time (Burns et al., 2017). A further study reported that anxiety decreased in people with dementia after receiving their diagnosis, particularly for those with high anxiety prior to the diagnosis (Carpenter et al., 2008). Studies on the perspectives of HCPs suggested that some people with dementia deny or minimise the diagnosis (Segers, 2009, Kaduszkiewicz et al., 2008). Studies exploring the perspectives of carers or family members found they reported feeling anxious (Segers, 2009, Laakkonen et al., 2008), uncertain (van Wijngaarden et al., 2018, Laakkonen et al., 2008), hopeless (Laakkonen et al., 2008), lonely (Laakkonen et al., 2008), that their hope and trust in the future was taken away (van Wijngaarden et al., 2018) and anxiety and uncertainty due to not knowing where to get help or what to do next (Laakkonen et al., 2008). One study found that carers reported a sense of relief and validation that their observations about something being wrong were correct, which in turn led to a sense of acceptance. However, this study also found that carers felt sad, terrified, overwhelmed, and worried (Champlin, 2020). HCPs reported feeling a need to manage their own emotional journey (Bennett et al., 2018). GPs reported a sense of trepidation regarding the disclosure (Phillips et al., 2012), and were hesitant and expressed worry regarding the negative psychological impact upon people with dementia of the diagnosis disclosure due to stigma (Abe et al., 2019).

Communication of the diagnosis

Communication was explored in 21 studies. There were conflicting findings regarding using explicit terms such as 'dementia' or specific labels like 'Alzheimer's disease' when communicating the diagnosis to people with dementia and carers. Five studies reported that such terminology should be used (Bennett et al., 2018, Grossberg et al., 2010) and was commonly used (Raicher et al., 2008, Nielsen et al., 2018, Bailey et al., 2019), but eight reported that HCPs tended not to use these terms (Zou et al., 2017, Zaleta et al., 2012, Segers, 2009, Phillips et al., 2012, Moore and Cahill, 2013, Milby et al., 2017, Kaduszkiewicz et al., 2008, Hansen et al., 2008). Reasons for not using specific terminology were that ambiguous language may be preferable when HCPs themselves are uncertain of the diagnosis (Zaleta et al., 2012, Milby et al., 2017), and unambiguous terms were not always helpful in facilitating the person with dementia's understanding (Peel, 2015). Other reasons included minimising distress (Milby et al., 2017, Bailey et al., 2019), avoiding negative connotations of the word 'dementia' (Phillips et al., 2012), and avoiding pathologising the condition (Abe et al., 2019). Cultural differences were highlighted, suggesting that colloquial terms were used because they were more familiar to the local community (Abe et al., 2019).

Considering communication patterns in consultations, one study found that HCPs tended to dominate the disclosure meeting by talking on average for 83% of the time. Emphasis shifted from the person with dementia to the carer even when the person with dementia was in the mild stages of the condition and still able to speak and contribute information (Wynn and Carpenter, 2017). Whilst patient-centred communication was noted in one study, findings suggested that aspects of communication such as emotional rapport-building were infrequent (Zaleta and Carpenter, 2010). Three studies indicated that written information should accompany disclosure meetings (Nielsen et al., 2018, Mastwyk et al., 2014, Grossberg et al., 2010).

People involved

There were mixed findings regarding who should disclose the diagnosis. One study suggested specialists should always take this role (Villars et al., 2010) with another suggesting that specialists could occupy a position of blame in contrast to the GP, who could provide support to patients (Phillips et al., 2012). However, this study also reported that GPs should take on the role of disclosure when a well-developed patient-doctor relationship existed because they would be known to the patient compared to a specialist. A Swiss survey reported that 75% of GPs disclosed the diagnosis themselves (Giezendanner et al., 2018). Other professionals have roles in disclosure, suggesting that discussing well-being should be undertaken by a multidisciplinary team (Vince et al., 2017), although psychiatrists wanted more time to discuss well-being during the disclosure to avoid being seen as someone who only diagnoses conditions and prescribes medication (Vince et al., 2017).

The majority of articles agreed it was beneficial for carers to accompany the person with dementia to disclosure meetings (Phillips et al., 2012, Page et al., 2015, Nielsen et al., 2018, Grossberg et al., 2010, Bradford et al., 2011, Lingler et al., 2016, Abe et al., 2019, Bailey et al., 2019, Giezendanner et al., 2018). Family members often wanted more information, and could receive education to help them cope in the future (Phillips et al., 2012, Bailey et al., 2019). Carers represent a reassuring presence for the HCP (Page et al., 2015), can help them communicate the diagnosis more effectively to the person with dementia (Grossberg et al., 2010), and help to recall details of the diagnosis (Bradford et al., 2011, Bailey et al., 2019). One study found that, within its sample, people with MCI showed a lack of health literacy, suggesting carers were necessary to help process and understand the information provided (Lingler et al., 2016). Further, one study suggested that carers are usually most troubled by symptoms of dementia, and using disclosure meetings to reassure them is

important (Abe et al., 2019). HCPs in one study suggested that fuller details of the diagnosis were disclosed to carers rather than people with dementia (Kaduszkiewicz et al., 2008). A key point here is the lack of people with dementia as participants in the included studies, which limits the ability to draw conclusions regarding their preferences for their own and others' involvement.

Attitudes towards diagnosis disclosure

Studies investigating HCPs' attitudes towards disclosing the diagnosis found it can be perceived as draining (Milby et al., 2017); they might feel like the 'grim reaper' when delivering bad news (Bennett et al., 2018), or worry that the process could ruin doctor-patient relationships (Kaduszkiewicz et al., 2008). Some psychiatrists may hold a medically rooted nihilistic and reductionist attitude due to a sense of hopelessness around potential interventions for people with dementia and a lack of appropriate services to support well-being (Vince et al., 2017). Geriatricians who did not provide information on progression and prognosis of Alzheimer's disease to the person with dementia reported this was because the person with dementia did not ask, or the HCP was either fearful of a depressive reaction or felt the knowledge was of no use (Segers, 2009).

Carers typically approached diagnosis disclosure as a useful event (Mormont et al., 2012), and felt that people with dementia had a right to know in order to begin treatment, face the condition positively, know what is happening to them, and plan for the future (Zou et al., 2017). Carers were divided on whether the diagnosis should be revealed in an up-front approach, or in stages (Mastwyk et al., 2014). Those who preferred an up-front approach felt it necessary for planning, and managing issues such as driving cessation. Carers felt empowered when HCPs explained how and where to get treatment (Mastwyk et al., 2014) and tended to prefer the HCP openly informing the person with

dementia of the diagnosis (Laakkonen et al., 2008). A good quality disclosure was associated with better carer adjustment in relation to sadness, depression, and acceptance (Woods et al., 2018).

Only two studies considered attitudes towards diagnosis disclosure from the perspective of people with dementia themselves, with one finding that people with dementia tended not to agree with or acknowledge the information disclosed by the HCP (Peel, 2015). The other study found that people with dementia would prefer to receive a direct disclosure even though it might be a shock (Mastwyk et al., 2014).

Use of diagnostic tests and assessments

Four studies suggest that, prior to the disclosure meeting, HCPs should discuss what people with dementia and carers can expect from assessments, especially from brain scans and biomarker testing, and potential limitations or implications of diagnostic tests (Visser et al., 2012, Porteri et al., 2010, Grill et al., 2017, Lingler et al., 2016). People with dementia and carers should have the choice to receive the results from assessments or not, and should have the opportunity to change their mind at any point (Porteri et al., 2010).

Three studies suggested that brain scans should be reviewed in disclosure meetings (Nielsen et al., 2018, Lingler et al., 2016, Grill et al., 2017) so people with dementia and carers can see the images.

Two studies offered caution regarding how results of amyloid scans were communicated, where explanations should state that presence of amyloid indicates a risk for developing dementia whilst absence of amyloid does not indicate absence of illness (Grill et al., 2017), and that biomarkers are not yet a diagnostic tool in themselves (Burns et al., 2017). One study advocated for provision of take-home materials to supplement the explanation of scans and assessments (Lingler et al., 2016).

Truth telling and deception

Three studies considered the aspect of truth telling or withholding the truth of the diagnosis from people with dementia. One study reported that HCPs felt a truthful diagnosis was not necessary due to a lack of effective treatments and potential impact on pre-existing symptoms of anxiety or depression (Porteri et al., 2010). Conversely, a different study found that providing a truthful diagnosis did not create a negative emotional impact for people with dementia or carers, and instead helped to relieve anxiety or depression for both (Carpenter et al., 2008). The third study reported difficulties in delivering the diagnosis as people with dementia may try to normalise their experience, and HCPs must balance this with not deceiving the person with dementia as to the diagnosis (Peel, 2015).

Timeliness

Three studies considered the timing of receiving a diagnosis of dementia, with one study reporting that nearly half of carers surveyed across five European countries felt diagnosis was delayed (Woods et al., 2018). Reasons for delay included people with dementia refusing to be assessed, negative professional attitudes, and being told there was no point in a diagnosis. Receiving timely diagnoses could assist people with dementia in remembering their diagnosis (Bradford et al., 2011), but another study indicated potential detriment to well-being if provided before a person had processed what is happening and accepted the changes they are experiencing (Vince et al., 2017).

Training and skills

As far as can be determined from the included studies, there is no specific training available in how to disclose a diagnosis of dementia. In two studies HCPs reported receiving training in breaking bad

news, attending conferences on the topic, or using general guidelines for diagnostic disclosure (Vince et al., 2017, Nielsen et al., 2018). Despite disclosure often being performed by specialists, two studies indicated that primary care physicians should have training on disclosing sensitively (Foley et al., 2017) and integrating disclosure into their consultations (Villars et al., 2010).

Discussion

This review provides the only up-to-date comprehensive account, based on a rigorous systematic literature search, of common practice around the world in disclosing a diagnosis of dementia from the perspectives of people with dementia, carers, and HCPs. These findings suggest that telling the person with dementia the diagnosis is now common practice. However, HCPs may experience discomfort in revealing the diagnosis and consequently use euphemisms to describe the syndrome rather than explicit terminology. Generally, if diagnosis disclosure is provided as a one-off event, and without discussion of hopeful aspects or emotional rapport building, it has a negative impact on people with dementia and carers. Carers report needing to know more about the future and prognosis, and their preference is for the diagnosis to be disclosed in a realistic yet hopeful way. HCPs would benefit from guidance and support in how to disclose the diagnosis, and the disclosure should be approached as a process involving a multidisciplinary team rather than as a singular event. The findings suggest progress in normalising the diagnosis and reducing stigma but highlight that there is still more to be done.

Disclosure was viewed as a negative process by HCPs who reported an attitude of hopelessness, and uncertainty around the exact diagnosis, prognosis, and how much people receiving the diagnosis already knows or can understand. HCPs highlighted that the information needed by people with dementia and carers is difficult to deliver due to the delicate balance between honesty and hope

(Bailey et al., 2016). HCPs do not appear comfortable with their position as someone who delivers bad news and can only provide limited treatment options. This review also identified that little consideration was given to patient-centred communication and expectations extending to cultural differences.

Our findings suggest that disclosures can cause people with dementia to suffer emotionally (Zou et al., 2017). Similarly, emotional rapport-building is identified as important yet may not be frequently used in disclosures (Zaleta and Carpenter, 2010), suggesting that HCPs are not prioritising the emotional impact of receiving a diagnosis as a key consequence of the meeting. Whilst disclosure tended to have a negative impact for people with dementia and their carers, carers did report that disclosure was a useful event that enabled them to organise treatment and support, and discussion of aetiology, progression, and causes was helpful. However, carers expressed a need to know more about the future and prognosis following diagnosis. This finding shows consistency with a previous review (Werner et al., 2013), but the present review shows a step forward in the dialogue around truth-telling, in that simply knowing the diagnosis itself is not enough. Carers need to know what will happen to the person with dementia in the future, beyond the diagnosis, and what ramifications this will have for themselves as carers.

Consistent with earlier reviews (Lecouturier et al., 2008, Werner et al., 2013) is the preference for a process approach to disclosure. This is supported by guidance from the UK Alzheimer's Society (Alzheimer's Society, 2018) and the British Psychological Society (Watts et al., 2018) which suggest that delivering information in one session is overwhelming and instead disclosure should be embedded within the care pathway. People with dementia and carers need more time and space to process information provided in the disclosure, which could be achieved using follow-up appointments. Using follow-up appointments could aid with retaining information, as in the general

population 34-88% of what is said in medical appointments is forgotten, depending on the type of information provided, where general recall is higher for a discussion, but lower for specific information such as regarding lifestyle interventions (Richard et al., 2017). This is important, given the range of topics covered in a diagnosis disclosure, and it is likely that this figure is higher for people experiencing cognitive changes. More opportunities to impart the same information, or presenting smaller amounts of information more than once, could help people remember the diagnosis and its implications, whilst providing space to explore the emotional impact of the diagnosis. However, it must be noted that increasing the number of appointments would require greater resources, without which an increase in waiting times is likely and this is not desirable either. Involving other agencies, such as third sector agencies, could be useful.

Strengths and limitations

This review used a comprehensive search strategy across several databases to identify as many relevant articles as possible, although some articles indexed in other databases may have been missed. The rigor of the systematic search and quality review can be seen in that searching was completed by two reviewers, allowing for discussion and justification for inclusion or exclusion of each article, and a sample of articles were assessed for quality by a third, independent reviewer which resulted in a high level of agreement. Quality assessment was not used in previous reviews of this topic area (Werner et al., 2013), and showing how this review has moved the discussion forwards by highlighting methodological issues that must be considered in future work. Despite studies being of a variety of designs and conducted in different settings, the findings are generally consistent, suggesting that this review has identified realistic trends. The perspectives of people with dementia, carers, and HCPs were captured in this review, ensuring that findings are relevant to the experience of all people involved in the disclosure, and any implications can consider each set of needs.

Only studies written in English were included, and therefore some findings may have been missed. However, studies from across the world were included and despite some contradictory findings, generally there was agreement, suggesting that studies in languages other than English may not have significantly changed the results if included. Studies of all designs were included and, although this renders it impossible to synthesise numerical findings into meaningful quantitative analyses, the integration of qualitative and quantitative findings should be considered a strength. One methodological consideration to acknowledge is that much of the research included in this review is reliant on self-report techniques, either through use of surveys or qualitative interviews. Whilst surveys can reach a broad audience, and interviews can elicit rich details about the experience of disclosure, both methods of data collection can be affected by bias, and it is challenging to reliably compare or contrast practices reported by HCPs with the impact they have on recipients (Plejert et al., 2017). Only eight of the 52 included studies used observational methods (Hillman, 2017, McCabe et al., 2019, Peel, 2015, Sakai and Carpenter, 2011, Wynn and Carpenter, 2017, Xanthopoulou et al., 2019, Zaleta and Carpenter, 2010, Zaleta et al., 2012).

Implications

Recommendations for clinical practice

Communication skills do not reliably improve with experience alone (Cantwell and Ramirez, 1997) and consequently further training, supervision, and regular reflection on practice may support HCPs in navigating uncertainties and managing their own emotional journey. For HCPs in specialist roles, training should be specific to disclosing a diagnosis of dementia rather than generally about breaking bad news, and supervision should cover managing the emotions of the person with dementia and

the carer, as well as their own emotional responses. Communication skills training is mandatory in the majority of training programmes for all HCPs (Moore et al., 2018), but training to develop skills in shared communication, to raise awareness of supporting people with dementia and carers to assert themselves and maintain their agency and power during the disclosure, is needed. HCPs may benefit from guidance in understanding and supporting cultural differences and sensitivities in diagnosis disclosure. However, it is recognised that training is resource-intensive and relies upon having appropriately trained individuals who are available to train and support others. This is likely to be difficult across disciplines and in time-pressured healthcare environments.

Pre-diagnostic counselling prior to disclosure could explore beliefs and expectations, and potentially mitigate negative impacts by ensuring people with dementia and carers are prepared. This may support people with dementia and carers to consider questions they could ask between meetings and provide greater opportunity to speak during disclosure meetings. Follow-up meetings could enable tailoring of information, an opportunity to re-confirm the diagnosis, and discussions of prognosis, future considerations, and access to local support. Involving multi-disciplinary teams could help to provide an holistic and hopeful disclosure, reducing the negative emotional burden on individual HCPs whilst also reducing the likelihood that the disclosure is viewed as a singular negative event by people with dementia and carers (Vince et al., 2017). Reassurance and a realistic sense of hope about the future should be emphasised throughout, and HCPs could discuss how people with dementia and their carers can maintain quality of life after diagnosis.

Recommendations for people with dementia and carers

Information about memory assessments and what typically happens could be provided through channels including posters or leaflets in GP surgeries and community spaces. Information about

what to expect when receiving the results of assessments may be provided ahead of disclosure meetings, although this could be distressing if information were given without having someone available to provide support or further explanations. People with dementia should be supported to ensure they can have someone attend the disclosure meeting with them if they wish. Encouraging people with dementia to arrange a follow-up appointment with their GP could be beneficial for asking further questions and considering the future implications.

Recommendations for research

Much of the research included in this review relies on recalling the disclosure experience, and there is disparity between viewpoints of people with dementia, carers, and HCPs. A sensible next step is to conduct research that directly observes disclosure meetings, considering all individuals involved. Whilst work in this area has already been undertaken involving people with dementia, carers, and HCPs (Peel, 2015), further work currently underway focuses on doctors only (Bailey et al., 2019, Xanthopoulou et al., 2019). More research that considers the three-way dialogue between people with dementia, carers, and HCPs, analysing what each brings to the disclosure and what each takes away, is needed. Most research to date is from the perspective of carers, with some from the perspective of HCPs. More research considering perspectives of people with dementia on diagnosis disclosure is needed to fully understand their wants and needs. Research combining all three perspectives is required to develop a realistic understanding of how disclosures can be best conducted to benefit everyone involved, more closely reflecting real practice.

Researchers must respect the agency and rights of people with dementia to participate in research. Earlier reviews (Werner et al., 2013, Lecouturier et al., 2008) have not explored power dynamics between individuals involved in disclosures, or the agency that people with dementia possess in the

interaction. Only two studies in this review specifically considered attitudes towards diagnosis disclosure from the perspective of the person with dementia, although other studies have explored different facets of the disclosure process. Less than half of the studies in this review recruited people with dementia, and of those that did, the number of participants with dementia was small. Developing an understanding of disclosure without involving people with dementia is inconsistent with patient-centred care. The lack of information regarding cultural differences in disclosure clearly shows that future research must explore this area to develop practices that support a culturally-sensitive disclosure process.

Future qualitative studies could demonstrate greater methodological quality by stating the underpinning philosophical perspective adopted by researchers during data collection and analysis, including reflexive statements to locate researchers culturally and theoretically. Increased awareness by journal editors and peer-reviewers regarding the reporting of qualitative methodology would encourage researchers to be transparent in their theoretical approaches.

Conclusions

Disclosing a diagnosis of dementia is a key process for people with dementia, carers, and HCPs. This review indicates that while changes in some aspects of disclosure have occurred over the last decade, disclosing a diagnosis of dementia remains a difficult and complex process, for which formal training and guidance is lacking. Receiving a diagnosis is generally a negative process for people with dementia, carers, and HCPs, and leaves carers in particular feeling uncertain over the prognosis and future of the person they care for. Pre-diagnostic counselling and follow-up appointments could enable realistic and hopeful discussions of the implications of receiving a diagnosis of dementia,

whilst reducing emotional burden on HCPs. This review highlights a need for more objective evidence that considers the perspectives of all individuals involved.

Acknowledgements

Special thanks to Alexander Humm (AH) for assisting with the quality review process.

References

- ABE, M., TSUNAWAKI, S., MATSUDA, M., CIGOLLE, C. T., FETTERS, M. D. & INOUE, M. 2019. Perspectives on disclosure of the dementia diagnosis among primary care physicians in Japan: a qualitatively driven mixed methods study. *BMC Fam Pract*, 20, 69.
- ABHAYARATNE, C., BLANCHARD, E., CARTWRIGHT, V. & GREALLY, S. 2019. MSNAP Fifth National Report. London: Royal College of Psychiatrists.
- ALZHEIMER'S SOCIETY 2018. Assessment and diagnosis: Factsheet 426LP. In: SOCIETY, A. S. (ed.). London: Alzheimer's Society.
- AROMATARIS, E. & MUNN, Z. (eds.) 2017. *Joanna Briggs Institute Reviewer's Manual*: The Joanna Briggs Institute.
- BAILEY, C., DOOLEY, J. & MCCABE, R. The Little Dance: Delicate Deliveries of Dementia Diagnoses: Emerging findings from the ShareD study focus groups with doctors. Royal College of Psychiatrists Old Age Faculty Scientific Meeting, March 9–11 2016 2016 Nottingham, UK.
- BAILEY, C., DOOLEY, J. & MCCABE, R. 2019. 'How do they want to know?' Doctors' perspectives on making and communicating a diagnosis of dementia. *Dementia-International Journal of Social Research and Practice*, 18, 3004-3022.
- BENNETT, C. E., DE BOOS, D. & MOGHADDAM, N. G. 2018. Developing a tool to support diagnostic delivery of dementia. *Dementia (London)*, 1471301217750936.
- BRADFORD, A., et al. 2011. Knowledge of documented dementia diagnosis and treatment in veterans and their caregivers. *Am J Alzheimers Dis Other Demen*, 26, 127-33.
- BUNN, F., et al. 2012. Psychosocial Factors That Shape Patient and Carer Experiences of Dementia Diagnosis and Treatment: A Systematic Review of Qualitative Studies. *Plos Medicine*, 9.
- BURNS, J. M., JOHNSON, D. K., LIEBMANN, E. P., BOTHWELL, R. J., MORRIS, J. K. & VIDONI, E. D. 2017. Safety of disclosing amyloid status in cognitively normal older adults. *Alzheimer's & Dementia*, 13, 1024-1030.
- CAMPBELL, K. H., STOCKING, C. B., HOUGHAM, G. W., WHITEHOUSE, P. J., DANNER, D. D. & SACHS, G. A. 2008. Dementia, diagnostic disclosure, and self-reported health status. *J Am Geriatr Soc*, 56, 296-300.
- CANTWELL, B. & RAMIREZ, A. J. 1997. Doctor-patient communication: a study of junior house officers. *Medical Education*, 31, 17-21.
- CARPENTER, B. D., et al. 2008. Reaction to a dementia diagnosis in individuals with Alzheimer's disease and mild cognitive impairment. *J Am Geriatr Soc*, 56, 405-12.

- CARUANA-PULPAN, O. & SCERRI, C. 2014. Practices in diagnosis, disclosure and pharmacotherapeutic management of dementia by general practitioners - a national survey. *Aging Ment Health*, 18, 179-186.
- CHAMPLIN, B. E. 2020. The informal caregiver's lived experience of being present with a patient who receives a diagnosis of dementia: A phenomenological inquiry. *Dementia-International Journal of Social Research and Practice*, 19, 375-396.
- CHRISP, T. A., THOMAS, B. D., GODDARD, W. A. & OWENS, A. 2011. Dementia timeline: journeys, delays and decisions on the pathway to an early diagnosis. *Dementia*, 10, 555-570.
- CONNELL, C. M., ROBERTS, J. S., MCLAUGHLIN, S. J. & CARPENTER, B. D. 2009. Black and white adult family members' attitudes toward a dementia diagnosis. *J Am Geriatr Soc*, 57, 1562-8.
- DEPARTMENT OF HEALTH 2015. Prime Minister's challenge on dementia 2020. In: DEPARTMENT OF HEALTH (ed.). London.
- DOOLEY, J., BAILEY, C. & MCCABE, R. 2015. Communication in healthcare interactions in dementia: a systematic review of observational studies. *Int Psychogeriatr*, 27, 1277-300.
- ECCLES, M. P., et al. 2009. Improving professional practice in the disclosure of a diagnosis of dementia: a modeling experiment to evaluate a theory-based intervention. *Int J Behav Med*, 16, 377-87.
- FOLEY, T., BOYLE, S., JENNINGS, A. & SMITHSON, W. H. 2017. "We're certainly not in our comfort zone": a qualitative study of GPs' dementia-care educational needs. *BMC Fam Pract*, 18, 66.
- GIEZENDANNER, S., et al. 2018. Early diagnosis and management of dementia in general practice - how do Swiss GPs meet the challenge? *Swiss Med Wkly*, 148, w14695.
- GRILL, J. D., et al. 2017. Communicating mild cognitive impairment diagnoses with and without amyloid imaging. *Alzheimers Res Ther*, 9, 35.
- GROSSBERG, G. T., CHRISTENSEN, D. D., GRIFFITH, P. A., KERWIN, D. R., HUNT, G. & HALL, E. J. 2010. The art of sharing the diagnosis and management of Alzheimer's disease with patients and caregivers: Recommendations of an expert consensus panel. *Primary care companion to the Journal of clinical psychiatry*, 12.
- HANSEN, E. C., HUGHES, C., ROUTLEY, G. & ROBINSON, A. L. 2008. General practitioners' experiences and understandings of diagnosing dementia: Factors impacting on early diagnosis. *Social Science & Medicine*, 67, 1776-1783.
- HILLMAN, A. 2017. Diagnosing dementia: Ethnography, interactional ethics and everyday moral reasoning. *Soc Theory Health*, 15, 44-65.
- INNES, A., SZYMZYNSKA, P. & STARK, C. 2012. Dementia diagnosis and post-diagnostic support in Scottish rural communities: Experiences of people with dementia and their families. *Dementia*, 13, 233-247.
- KADUSZKIEWICZ, H., BACHMANN, C. & VAN DEN BUSSCHE, H. 2008. Telling 'the truth' in dementia- Do attitude and approach of general practitioners and specialists differ? *Patient Education & Counseling*, 70, 220-226.
- KARNIELI-MILLER, O., et al. 2012. Expectations, experiences, and tensions in the memory clinic: the process of diagnosis disclosure of dementia within a triad. *Int Psychogeriatr*, 24, 1756-1770.
- LAACKONEN, M. L., et al. 2008. How do elderly spouse care givers of people with Alzheimer disease experience the disclosure of dementia diagnosis and subsequent care? *J Med Ethics*, 34, 427-30.
- LECOUTURIER, J., et al. 2008. Appropriate disclosure of a diagnosis of dementia: identifying the key behaviours of 'best practice'. *BMC Health Serv Res*, 8, 95-95.
- LEE, L. & WESTON, W. W. 2011. Disclosing a diagnosis of dementia: helping learners to break bad news. *Can Fam Physician*, 57, 851-2, e270-2.
- LIM, Y. Y., MARUFF, P., GETTER, C. & SNYDER, P. J. 2016. Disclosure of positron emission tomography amyloid imaging results: a preliminary study of safety and tolerability. *Alzheimer's & Dementia*, 12, 454-458.

- LINGLER, J. H., et al. 2016. Development of a standardized approach to disclosing amyloid imaging research results in mild cognitive impairment. *Journal of Alzheimer's Disease*, 52, 17-24.
- MANTHORPE, J., et al. 2013. From forgetfulness to dementia: clinical and commissioning implications of diagnostic experiences. *British Journal of General Practice*, 63, 69-75.
- MASTWYK, M., AMES, D., ELLIS, K. A., CHIU, E. & DOW, B. 2014. Disclosing a dementia diagnosis: what do patients and family consider important? *Int Psychogeriatr*, 26, 1263-72.
- MCCABE, R., PAVLICKOVA, H., XANTHOPOULOU, P., BASS, N. J., LIVINGSTON, G. & DOOLEY, J. 2019. Patient and companion shared decision making and satisfaction with decisions about starting cholinesterase medication at dementia diagnosis. *Age and Ageing*, 48, 706-713.
- MILBY, E., MURPHY, G. & WINTHROP, A. 2017. Diagnosis disclosure in dementia: Understanding the experiences of clinicians and patients who have recently given or received a diagnosis. *Dementia (London)*, 16, 611-628.
- MOORE, P. M., RIVERA, S., BRAVO-SOTO, G. A., OLIVARES, C. & LAWRIE, T. A. 2018. Communication skills training for healthcare professionals working with people who have cancer. *The Cochrane database of systematic reviews*, 7, CD003751-CD003751.
- MOORE, V. & CAHILL, S. 2013. Diagnosis and disclosure of dementia - A comparative qualitative study of Irish and Swedish General Practitioners. *Aging Ment Health*, 17, 77-84.
- MORMONT, E., DE FAYS, K. & JAMART, J. 2012. Experiences of the patients and their caregivers regarding the disclosure of the diagnosis of Alzheimer's disease: a Belgian retrospective survey. *Acta Neurol Belg*, 112, 249-254.
- NIELSEN, T. R., et al. 2018. The process of disclosing a diagnosis of dementia and mild cognitive impairment: A national survey of specialist physicians in Denmark. *Dementia (London)*, 1471301218777443.
- PAGE, S., DAVIES-ABBOTT, I., INGLE, S. & BEE, P. 2015. 'Rydym Eisau Gwybod'-the dementia diagnosis disclosure preferences of people in North Wales. *Int J Geriatr Psychiatry*, 30, 108-110.
- PEEL, E. 2015. Diagnostic communication in the memory clinic: a conversation analytic perspective. *Aging Ment Health*, 19, 1123-1130.
- PHILLIPS, J., et al. 2012. Difficulties in disclosing the diagnosis of dementia: a qualitative study in general practice. *Br J Gen Pract*, 62, e546-53.
- PLEJERT, C., JONES, D. & PEEL, E. L. U. C. H. H. N. 2017. Life with Dementia: Relations, Responses and Agency in Everyday Life. *Life with Dementia: Relations, Responses and Agency in Everyday Life*. London: Palgrave Macmillan.
- PORTERI, C., GALLUZZI, S., GEROLDI, C. & FRISONI, G. B. 2010. Diagnosis disclosure of prodromal Alzheimer disease-ethical analysis of two cases. *Can J Neurol Sci*, 37, 67-75.
- RAICHER, I., et al. 2008. Alzheimer's disease diagnosis disclosure in Brazil: a survey of specialized physicians' current practice and attitudes. *Int Psychogeriatr*, 20, 471-481.
- RICHARD, C., GLASER, E. & LUSSIER, M. T. 2017. Communication and patient participation influencing patient recall of treatment discussions. *Health Expectations*, 20, 760-770.
- ROBINSON, L., et al. 2011. The transition to dementia--individual and family experiences of receiving a diagnosis: a review. *Int Psychogeriatr*, 23, 1026-1043.
- ROBINSON, L., TANG, E. & TAYLOR, J.-P. 2015. Dementia: timely diagnosis and early intervention. *BMJ*, 350, h3029.
- SAKAI, E. Y. & CARPENTER, B. D. 2011. Linguistic features of power dynamics in triadic dementia diagnostic conversations. *Patient Educ Couns*, 85, 295-8.
- SAMSI, K., et al. 2014. Negotiating a labyrinth: experiences of assessment and diagnostic journey in cognitive impairment and dementia. *Int J Geriatr Psychiatry*, 29, 58-67.
- SEGRS, K. 2009. What Belgian geriatricians tell their patients with Alzheimer's disease and why: a national survey. *Acta Neurol Belg*, 109, 283-93.

- SHIMIZU, M. M., RAICHER, I., TAKAHASHI, D. Y., CARAMELLI, P. & NITRINI, R. 2008. Disclosure of the diagnosis of Alzheimer's disease: caregivers' opinions in a Brazilian sample. *Arq Neuropsiquiatr*, 66, 625-30.
- STOKES, L. A., COMBES, H. & STOKES, G. 2014. Understanding the dementia diagnosis: the impact on the caregiving experience. *Dementia (London)*, 13, 59-78.
- VAN DEN DUNGEN, P., et al. 2014. Preferences regarding disclosure of a diagnosis of dementia: a systematic review. *Int Psychogeriatr*, 26, 1603-1618.
- VAN WIJNGAARDEN, E., VAN DER WEDDEN, H., HENNING, Z., KOMEN, R. & THE, A. M. 2018. Entangled in uncertainty: The experience of living with dementia from the perspective of family caregivers. *PLoS One*, 13, e0198034.
- VILLARS, H., et al. 2010. The primary care physician and Alzheimer's disease: an international position paper. *J Nutr Health Aging*, 14, 110-20.
- VINCE, A., CLARKE, C. & WOLVERSON, E. L. 2017. The meaning and experience of well-being in dementia for psychiatrists involved in diagnostic disclosure: a qualitative study. *Int Psychogeriatr*, 29, 93-104.
- VISSER, P. J., WOLF, H., FRISONI, G. & GERTZ, H.-J. 2012. Disclosure of Alzheimer's disease biomarker status in subjects with mild cognitive impairment. *Biomarkers in Medicine*, 6, 365-368.
- WATTS, S., MCCABE, R. & GUSS, G. 2018. Communicating a diagnosis of dementia. Leicester: The British Psychological Society.
- WERNER, P., KARNIELI-MILLER, O. & EIDELMAN, S. 2013. Current knowledge and future directions about the disclosure of dementia: a systematic review of the first decade of the 21st century. *Alzheimers Dement*, 9, e74-88.
- WOODS, B., et al. 2018. Timely diagnosis of dementia? Family carers' experiences in 5 European countries. *Int J Geriatr Psychiatry*.
- WOODS, B., et al. 2019. Timely diagnosis of dementia? Family carers' experiences in 5 European countries. *Int J Geriatr Psychiatry*, 34, 114-121.
- WORLD HEALTH ORGANIZATION. 2020. *Dementia Fact Sheet* [Online]. World Health Organization. Available: <https://www.who.int/news-room/fact-sheets/detail/dementia> [Accessed 4th March 2020 2020].
- WYNN, M. J. & CARPENTER, B. D. 2017. Discourse Features Among Providers, Patients, and Companions and Their Effect on Outcomes of Dementia Diagnosis Disclosure. *J Gerontol B Psychol Sci Soc Sci*.
- XANTHOPOULOU, P., DOOLEY, J., MEO, I., BASS, N. & MCCABE, R. 2019. Patient and companion concerns when receiving a dementia diagnosis: an observational study of dementia diagnosis feedback meetings. *Ageing & Society*, 39, 1782-1805.
- ZALETA, A. K. & CARPENTER, B. D. 2010. Patient-centered communication during the disclosure of a dementia diagnosis. *Am J Alzheimers Dis Other Dement*, 25, 513-20.
- ZALETA, A. K., et al. 2012. Agreement on diagnosis among patients, companions, and professionals after a dementia evaluation. *Alzheimer Disease & Associated Disorders*, 26, 232-237.
- ZOU, Y., et al. 2017. Caregivers' attitude toward disclosure of Alzheimer's disease diagnosis in Urban China. *Int Psychogeriatr*, 29, 1849-1855.

Figure 1: PRISMA flow diagram of included studies

Table 1: Main findings and study details of included studies

Reference	Participants	Setting	Design	Aim	Main findings	JB1 %
Albe et al., 2019: Perspectives on disclosure of the dementia diagnosis among primary care physicians in Japan: a qualitatively driven mixed methods study	24 primary care physicians	Japan	Qualitative semi-structured interviews and a ranking task	To investigate how primary care physicians in Japan approach disclosure of a dementia diagnosis to patients and family members	Diagnoses were disclosed jointly to the person with dementia and their family members for all participants, and cooperation and well-being of family members was important to physicians in maintaining quality of life for the person with dementia. Physicians were concerned about the potential negative psychological impact on patients, the degree to which patients understood the information provided, and the stigma associated with dementia. Almost half of the sample reported they did not receive training in disclosing a diagnosis of dementia and were unsure if their approach was appropriate.	70%
Bailey et al., 2018: 'How do they want to know?' Doctors' perspectives on making and communicating a diagnosis of dementia	15 doctors (13 old age psychiatrists and 2 geriatricians)	UK	Qualitative focus groups	To investigate the views and experiences of doctors making and delivering diagnoses in memory clinics	Organisation of some memory clinics involves allied health professionals conducting assessments, so doctors disclosing the diagnosis can be meeting that patient for the first time, which feels unnatural and makes it difficult for the doctor to gauge the patients' readiness and expectations. The diagnosis was seen as a useful framework to involve other services and open discussions about possible therapies. Participants reported managing the different audiences (patient and companion) in the consultation was challenging and balancing the needs of both could lead to conflict. Few participants reported receiving specific training and most relied on basic principles taught in medical school, and there was a lack of supervision and support in discussing the emotional impact on doctors themselves. Participants tended to use the word dementia, but some approached it gradually by introducing the idea of memory problems first. There was a tension between presenting a hopeful picture, whilst also being honest, and reflecting that there is uncertainty in the diagnosis. Participants reflected that due to service pressures there just wasn't enough time to cover everything they wanted to in a disclosure meeting and consequently follow-up appointments are crucial.	70%
Bennett, et al., 2018: Developing a tool to support diagnostic delivery of dementia	14 interviews, 4 clinicians, 4 patients, 5 companions 13 took part in focus groups, 2 PwD, 4 companions 7 clinicians	MAS clinics in a large UK city	Qualitative interviews with thematic analysis to produce a tool for clinicians evaluated in focus groups	To develop a tool specific to dementia diagnostic delivery based on clinician, patient and companion experiences	Themes: 1. Overcoming barriers to good delivery, 2. Navigation of multiple journeys (attendee's emotions, clinician's emotions) 3. Overt tasks (develop a supporting relationship, promote consent and choice, develop understanding, be patient centred, provide emotional support) 4. Covert tasks (Overcoming power imbalance between clinician and patient, continual adaptation, awareness and management of dynamics)	75%

					Focus groups: patients would like information about the appointment beforehand. Some experienced clinicians may not want a good practice guide	
Bradford et al., 2011: Knowledge of documented dementia diagnosis and treatment in veterans and their caregivers	132 dementia patients and 183 caregivers (122 were in a dyad)	Medical centre in Houston USA	Comparison of medical records with self-reported questionnaire	To determine the extent to which patients' and caregivers' perceptions of dementia diagnosis and prescribed medications are consistent with information in patients' medical records. And to compare patients' and caregivers' perceptions to one another to explore the extent to which knowledge of dementia diagnosis and treatment is shared within the dyad.	67% of carers and 24% of patients were aware of their diagnosis of dementia of some kind. For patients this may be because of lack of ability to recall. Unclear whether findings are attributable to participant's factual knowledge or variation in disclosure practices. Patients more likely to recall that they had been prescribed a memory enhancing drug. Only in 10% of dyads did both caregiver and patient agree on the dementia diagnosis indicating that interventions should be dyadic.	80%
Burns et al., 2017: Safety of disclosing amyloid status in cognitively normal older adults	97 cognitively normal participants who were involved in a larger trial	University of Kansas Alzheimer's Disease Center, USA	Part of a larger trial evaluating the effects of exercise on AD biomarkers. Mood was assessed using validated measures before the scan, at the disclosure visit, 6 weeks and 6 months after disclosure	To evaluate safety and tolerability of disclosure of elevated amyloid levels shown on PET scans	There were no differences between the amyloid elevated group and the amyloid not-elevated group for depression at any time point. Anxiety increased in amyloid elevated participants at a low level on the day of disclosure but was not sustained at 6 weeks or 6 months. Higher levels of anxiety and depression at baseline were modestly predictive of levels of anxiety and depression at follow-up. Amyloid elevated participants did not regret learning the outcome of their scan. The authors note that discussion of the scan frames the results conceptually as a risk factor for development of AD rather than as a diagnostic tool. Further, the authors stress using terms 'elevated' rather than positive to avoid confusion of positive being beneficial.	90%
Campbell et al., 2008: Dementia, diagnostic disclosure, and self-reported health status	149 patients with diagnosis of dementia	3 clinical referral sites USA	Secondary data analysis of survey	To investigate the general awareness of cognitive impairment in persons with documented dementia, evaluate the subject's recall of a diagnostic disclosure from a physician and their recollection of the discussion, and	Thirty nine (26.2%) subjects reported being told by a physician about a diagnosis of dementia or memory problems. This recall was associated with younger age (Po.001), male sex (P5.04), and higher education level (P5.02). African Americans reported poorer self-rated health scores (odds ratio (OR) 52.4, 95% confidence interval (CI) 51.1–5.1). Persons who reported being told by a physician of a diagnosis of dementia were more likely to report poorer self-rated health (OR52.5, 95% CI 1.1–5.5).	90%

				determine whether this awareness of cognitive impairment or the recall of diagnostic disclosure is associated with poorer self-rated health scores.		
Carpenter et al., 2008: Reaction to a dementia diagnosis in individuals with Alzheimer's disease and mild cognitive impairment	62 Participant-companion dyads	Memory and Aging Project and the Alzheimer's Disease Research Centre (Washington, USA)	Before and after diagnosis questionnaire	To examine the psychological reaction to receiving a dementia diagnosis in individuals attending an Alzheimer's Disease Research Centre (ADRC)	Most individuals and their companions seeking a dementia evaluation do not experience adverse psychological reactions when they receive diagnostic feedback. Symptoms of anxiety and depression remain stable or even decline immediately after diagnosis. Severity of dementia, age, sex, and education appear to have no significant effect on this outcome. Little change was seen in depressive symptoms. In contrast, symptoms of anxiety seem to decrease after diagnostic feedback. In particular, individuals who started the evaluation process with high levels of anxiety were likely to experience significant relief after they received diagnostic information.	80%
Caruana-Pulpan & Scerri 2014: Practices in diagnosis, disclosure and pharmacotherapeutic management of dementia by general practitioners – a national survey.	GPs in Malta 193	Survey, Malta	National survey	To explore, via a national survey, the practice patterns of GPs with respect to their ability to diagnose, disclose and pharmacotherapeutically manage dementia in their primary care setting	A considerable number of GPs (62.2%) indicated that they do not routinely disclose the diagnosis, even though more than half of the respondents were in favour of the fact that disease disclosure may actually help the patient and the caregiver in future planning and treatment decisions. On disclosing, GPs are unsure of the suitable terminology to use in describing the condition to their patients and/or caregivers, with dementia being the most likely used term (33.7%) followed by memory problems (26.4%). Most physicians would prefer to disclose on being sure of a correct diagnosis and would do so to both the patient and the caregiver or relative.	80%
Champlin 2020: The informal caregiver's lived experience of being present with a patient who receives a diagnosis of dementia: A phenomenological inquiry	12 informal caregivers	USA	Qualitative face-to-face interviews with a phenomenological analysis approach	To understand the informal caregiver's experience of being present with a loved one when he or she receives a diagnosis of dementia, and what the constituents of the meaning that they assign are	Caregivers are usually aware that there is something wrong with the person they care for and can experience feelings of relief and validation when the diagnosis is disclosed, which helps lead to a sense of acceptance. Alongside this were emotional responses that involved feeling sad, terrified, worried and overwhelmed, but coupled with a need to stay strong. Caregivers watched for an emotional response in the person with dementia when the diagnosis was disclosed, and reported seeing fear, sadness, and perhaps confusion, but sometimes no response. Caregivers reported wanting a road map to help them navigate the future and understand how they might care for the person with dementia.	100%
Connell et al., 2009: Black and white adult family members' attitudes toward a dementia diagnosis	178 adults with varying exposure to AD (including first-degree relatives of people with AD, current and former	Survey in Boston/Atlanta USA	Survey using the Treatment and Illness Perceptions Survey	The primary purpose of the present study was to examine potential benefits of and barriers to diagnosis from the perspective of black and white adults directly	Family members affected by AD endorsed a wide range of the benefits but few of the barriers to obtaining a diagnosis examined in this study. The most frequently endorsed benefits pertained to obtaining information, finding out what was wrong, and prompting future plans. In addition to the lack of a cure for AD, the beliefs that little can be done for someone with AD, that there is a lack of effective treatment, and that obtaining a	100%

	primary caregivers of people with AD, and those with neither an affected first degree relative nor an AD caregiving history			affected by AD; a secondary purpose was to explore black–white differences in these perceptions.	diagnosis was a demanding process for families were the barriers most frequently endorsed. Black respondents expressed more-positive views of obtaining a diagnosis than their white counterparts. Black respondents more likely to strongly endorse a number of benefits, but they were also less likely to view the fact that there is currently no cure or effective treatment as a barrier to diagnosis	
Eccles et al., 2009. Improving professional practice in the disclosure of a diagnosis of dementia: a modeling experiment to evaluate a theory-based intervention.	664 individuals from 179 teams. All professionals who may deliver a diagnosis of dementia	Questionnaire sent to individuals within OAMHTs in England	A four-arm randomized controlled trial of the effect of one theory-based and two pragmatic interventions on the intentions of a random sample of members of OAMHTs	To evaluate a theory based intervention alongside two pragmatic interventions. A modelling experiment with the primary outcome of intention	None of the interventions changed intentions or behavioural simulation scores in relation to finding out what the patient already knows/suspects about their diagnosis, using the actual words ‘dementia’ or ‘Alzheimer’s disease’ when talking to the patient or exploring what the diagnosis means to the patient.	90%
Foley et al., 2017: "We're certainly not in our comfort zone": a qualitative study of GPs' dementia-care educational needs	14 GPs, 12 family carers, and 5 PwD	Ireland	Qualitative interviews	To explore GP's dementia care education needs to inform the development of a primary care dementia educational programme	All participants expressed the importance of disclosure and the need for GPs to receive training on how to disclose sensitively. The need for GPs to provide information on sources of support and local community-based health and social care services was widely expressed. Some GPs recognised that their role included supporting people through the emotional impact of what can be a devastating diagnosis. However, GPs tended not to identify counselling as a training need, even though carers and PwD did.	85%
Giezendanner et al., (2018): Early diagnosis and management of dementia in general practice – how do Swiss GPs meet the challenge?	882 GPs	Switzerland	Survey	To explore GPs' approach to the diagnosis, disclosure and management of dementia, and their perception of the provision of care and health services for individuals with dementia via a national survey.	Three quarters of respondents disclosed the diagnosis themselves, with only 9% reporting that they almost never or never took on this role. Almost 90% reported that disclosures involved the person with dementia and their family members. Disclosures lasted an average of 28.5 minutes.	100%
Grill et al., 2017: Communicating mild cognitive impairment diagnoses with and without amyloid imaging	19 experts	US	Workgroup meeting	To identify recommendations and best practices for delivering a diagnosis of MCI	Patients should be provided with a written summary of the diagnosis and treatment recommendations, services available, and local resources. Careful, honest and compassionate dialogue should be used to help patients validate and understand their condition. Patients should have the opportunity to discuss whether they would like further testing, e.g. amyloid imaging, and what the implications are for clinical management. The clinician should discuss what the patient and their family can expect from the	85%

					scan, and the limitations of it. The results of amyloid scans should be delivered in person and described using terminology related to the presence or absence of amyloid and not the amount or any link to severity. Clinicians should explain that negative scans do not mean absence of illness, and that positive scans represent a risk for further decline. Clinicians may wish to review the images of the scans with patients.	
Grossberg et al., 2010: The art of sharing the diagnosis and management of Alzheimer's disease with patients and caregivers: Recommendations of an expert consensus panel	6 academic or practising physicians	US	Roundtable discussion with an expert consensus panel	To generate recommendations for primary care physicians in communicating the diagnosis and management of AD	The diagnosis should be a process rather than an event, over several visits, to introduce the possibility of a diagnosis gradually. Family members should be present at disclosure and subsequent visits to help the physician to communicate the diagnosis effectively. Diagnoses should be disclosed in a private, comfortable, quiet location, with ample time for the visit. Distractions such as phone calls should be avoided. Specific language e.g. Alzheimer's should be used unless cultural, educational, or other factors deem this inappropriate. Because of the negative connotations, physicians should try to emphasise hopeful aspects, such as functioning that is preserved and capabilities that the PwD has. Physicians should position themselves as a partner of and advocate for the PwD and their family, and a tailored approach should be taken. Physicians should discuss with carers what stage the PwD is at and the likely prognosis for the next six months, and what resources may be helpful. Basic literature should be provided. Discussions about driving should begin early in process.	100%
Hansen et al., 2008: General practitioners' experiences and understandings of diagnosing dementia: Factors impacting on early diagnosis	25 GPs	Australia	Focus groups and semi-structured interviews	To achieve a greater understanding of dementia diagnosis from the perspective of GPs	GPs reported that rather than disclose the diagnosis using explicit terms, a discussion over a number of consultations is preferred, where the PwD can begin to realise for themselves that they have memory problems. GPs made judgements about whether the PwD would be comfortable with explicit terms and when it would be appropriate to talk to them about the issue.	80%
Hillman 2016: Diagnosing dementia: Ethnography, interactional ethics and everyday moral reasoning	51 consultations observed 13 interviews with memory clinic staff	UK	Observations in memory clinics	To explore the construction of morals whilst highlighting the social, collaborative, and processual nature of reaching a diagnosis	Each person should be treated individually and there are no text book rules about how to disclose. Clinicians expressed a tension between recognising that the patient is an individual with the capacity to make free and reasoned choices, and that the diagnosis cannot be disentangled from the perceptions, needs and concerns of other people in the patient's life who might need more information. Disciplinary and organisational cultures play a role in framing the consultation, where the impetus is on achieving the correct diagnosis in a reliable way, rather than on how it is delivered. Clinicians face a tension between wanting to use time as a resource to build up to delivering the diagnosis, but also feeling under pressure to not provide another appointment and instead	90%

					<p>to apply a diagnostic label, diagnose promptly and free up appointments for other people in the face of increasing caseloads.</p> <p>Visual evidence from CT scans can help clinicians frame the diagnosis in an objective way and show the transition from memory problems to a diagnosis, and move the conversation towards treatment and intervention plans.</p>	
Innes et al., 2014: Dementia diagnosis and post-diagnostic support in Scottish rural communities: Experiences of people with dementia and their families	18 participants (6 PwD and 12 carers)	Scotland	Qualitative interviews	To report service user views about diagnostic processes in a remote and rural region	<p>Most diagnoses were delivered face to face by a clinician. Participants wanted to receive an explanation and more information and support regarding available care. Participants reported that nothing was explained when they were diagnosed. Participants reported feeling the diagnosis came as a shock, despite an awareness of their memory problems prior to assessment.</p>	70%
Kaduszkiewicz et al., 2008: Telling 'the truth' in dementia-Do attitude and approach of general practitioners and specialists differ?	30 GPs participated in qualitative interviews 307 respondents to the questionnaire (211 GPs and 96 specialists)	Germany	Qualitative interviews and a questionnaire developed from the interview data	To systematically investigate differences between GPs and specialists with regards to diagnosis and disclosure of dementia	<p>GPs reported that patients deny their diagnosis when it is disclosed and try to convey that all is well.</p> <p>GPs worried about ruining the doctor patient relationship and avoid conflict with the patient.</p> <p>21 GPs reported using language other than dementia or Alzheimer's and instead use terms like normal ageing process, or attribute it to circulatory issues.</p> <p>Both specialists and GPs tended to report more fuller details of the diagnosis to the relatives rather than the patient, and use explicit terms. Only one third of specialists and half of GPs used the terms Alzheimer's and dementia with patients.</p> <p>A large proportion of GPs strongly (35%) or partially (40%) confirmed that patients felt ashamed when confronted with signs of cognitive impairment. Results from specialists were similar.</p> <p>50% of GPs and 30% of specialists were interested in further training concerning communication with PwD and relatives.</p>	75%
Karneili-Miller et al., 2012: Expectations, experiences, and tensions in the memory clinic: the process of diagnosis disclosure of dementia within a triad	10 patients and 17 companions	Two memory clinics in Israel	Qualitative interviews using grounded theory after the visit to the memory clinic	To identify patients' and companions' expectations, perceptions, and experiences regarding first time encounters that deal with assessment and disclosure of the dementia diagnosis	<p>Many patients expressed disappointment or discontent following the consultations due to an absence of tangible solutions or due to the physician's style of interaction and communication with the patient and companion. For example, patients felt disempowered when physicians spoke directly to the companion instead of them. There is a difference in perspective between patients who endorsed their memory difficulties and those who did not, with the latter experiencing more offense.</p> <p>Companions wanted an explicit explanation of what they can and should do, where they might receive support and guidance. However, companions expressed that they were not given solutions and guidance.</p> <p>Some companions felt a follow-up session to deepen their understanding was necessary. The lack of details provided in the session left companions feeling insecure about how to proceed.</p>	70%

					<p>Some companions reported that the physician expressed impatience and even contempt towards the PwD, making rude interruptions.</p> <p>Some companions however expressed that they were glad someone was listening and was sympathetic to their feelings. Companions whose struggles and efforts were recognised and acknowledged felt reassured and empowered.</p>	
Laakkonen et al., 2008: How do elderly spouse care givers of people with Alzheimer disease experience the disclosure of dementia diagnosis and subsequent care?	1214 spousal carers of people with AD (1943 sampled to participate) 63 spousal carers participated in the qualitative part	Finland	Postal questionnaire and qualitative interviews	To explore participants experiences regarding diagnosis disclosure and subsequent need for advance care planning	<p>97% of carers preferred that the physician openly informed the PwD of the dementia diagnosis. 55% of the carers felt their spouse had developed depressive symptoms after disclosure, and 68% of carers felt that their awareness of the dementia had caused them grief or symptoms of depression.</p> <p>Carers in the qualitative study described feelings of hopelessness and loneliness, with particular examples occurring when they had not been invited for a follow-up appointment with the physician. Carers expressed feelings of uncertainty and anxiety, due to not knowing where to get help or what to do next. Carers felt disappointed with the lack of support and follow-up care, and felt uncertain about the prognosis.</p> <p>Some carers felt guilty about not asking enough questions, and some reported not knowing the right questions to ask. Carers expressed a desire for a further appointment once they had absorbed the information and understood it better.</p>	80%
Lecouturier et al., 2008: Appropriate disclosure of a diagnosis of dementia: identifying the key behaviours of 'best practice'	4 PwD 6 informal carers 8 panellists (health and social care professionals)	UK	Mixed methods approach involving a literature review, semi-structured interviews, and a consensus panel process involving a questionnaire and a meeting	To identify key components of the process of disclosure and to identify the range of disclosure behaviours using three different methods	<p>The literature review revealed a total of 199 components of appropriate disclosure.</p> <p>The interviews identified 112 behaviours.</p> <p>The questionnaire completed by the panellists identified 55 behaviours.</p> <p>Of the total 220 behaviours identified, 109 overlapped. Behaviours could be grouped into 8 categories: 1. Preparing for disclosure, 2. Integrating family members, 3. Exploring the patient's perspective, 4. Disclosing the diagnosis, 5. Responding to patient's reactions, 6. Focusing on QoL and well-being, 7. Planning for the future, 8. Communicating effectively.</p>	70%
Lee & Weston, 2011: Disclosing a diagnosis of dementia: Helping learners to break bad news		Canada	Opinion piece	To provide advice and strategies for disclosure of a dementia diagnosis, especially for those teaching others how to do it	<p>Suggestions for disclosure include: determining what the patient already knows about dementia and addressing misconceptions that may have arisen from experiences. Dementia might be described as part of a continuum of memory loss, with emphasis placed on preservation of function in the early stages.</p> <p>Provide realistic hope by highlighting individual variation in the manifestation and progression of dementia, and availability of treatment options. Healthcare professionals may discuss how to manage dementia and therapeutic options available.</p> <p>Healthcare professionals should emphasise non-abandonment and facilitate a caring committed relationship between PwD and the family physician.</p>	80%

Lim et al., 2016: Disclosure of positron emission tomography amyloid imaging results: a preliminary study of safety and tolerability	11 participants who were part of a larger study (n=63) who wished to know their biomarker results	Academic memory disorder clinics, Rhode Island, USA	Part of a larger trial to investigate pre-clinical AD biomarkers. Participants who wished to know their status were told and then completed a follow-up psychoeducational programme and structured interviews.	To evaluate the consequences of Amyloid Beta (AB) disclosure on mood, subjective sense of memory impairment, lifestyle, and perceived risks of AD.	Participants who had a negative AB result were relieved but conscious it could change over time. Participants with a positive AB result were anxious but not surprised, and had shared this information with others and sought additional information on the internet. AB positive participants had made lifestyle changes, experienced no negative effects on their mood or subjective sense of memory impairment. A psychoeducational brochure provided helped participants to understand the link between environmental and genetic risk factors and the future progression to AD, and they found it useful and informative. The brochure did change perceptions of risk for participants (either AB positive or negative).	100%
Lingler et al., 2016: Development of a standardized approach to disclosing amyloid imaging research results in mild cognitive impairment	10 dyads (carer and person with MCI) involved in a simulated disclosure and one to one interviews, and 8 of these (4 with MCI and 4 carers) participated in a focus group	Alzheimer's Disease Research Center, University of Pittsburgh, USA	Simulated disclosures of PET results (4 positive, 4 negative, and 4 inconclusive) with one to one interviews to complete a survey, and then a focus group with 8 of the participants	To test materials developed for use prior to amyloid imaging and when disclosing results of amyloid imaging in the context of MCI	Surveys revealed that participants were satisfied with the disclosure process. All participants had also taken a health literacy test, and half of those with MCI showed a lack of health literacy, confirming the need to have disclosure sessions with a companion present. A theme from the focus group of best practice recommendations suggested the following ideas: offer pre-test counselling, use clear graphics, review patients' brain image scans in the disclosure, offer take home materials describing follow-up options, call patients post-disclosure to answer emerging questions, and communicate seamlessly with primary care providers. A second theme was that knowledge is power, and despite the outcome of the tests participants generally felt that knowing enabled them to be strong and to make decisions about their futures.	60%
Manthorpe et al., 2013: From forgetfulness to dementia: clinical and commissioning implications of diagnostic experiences	27 people with memory problems and 26 supporters or carers (20 of which were matched pairs)	UK memory clinics	Qualitative interviews	To increase understanding of the experiences of people developing dementia and of their carers, to inform practice and decision making	Patients and carers felt that communication wasn't necessarily a dialogue as although there was time for questions in the consult, many did not know what to ask or what information they might need. Some felt they received enough information, but others felt their concerns and questions were disregarded by physicians telling them they were okay. Support tended to be generic rather than person-centred and in response to their concerns.	70%
Mastwyk et al., 2014: Disclosing a dementia diagnosis: what do patients and family consider important?	32 patient and carer dyads	Australian memory clinics	Semi-structured interviews and use of feedback sheets to record what was discussed during the appointment	To identify helpful strategies for clinicians in meeting the wants and needs of this patient group and those of their families	Several patients reported that the disclosure should be direct, even though it would be a shock, although some patients felt it depended on the individual and should be done sensitively. Carers' views were very similar. Patients felt that the doctor should be sure of the diagnosis before it was disclosed. Attributes of doctors considered a requirement for this role were supportive, being a good listener, and being easy to understand.	65%

					<p>Carers felt that they did not receive enough information during the disclosure.</p> <p>55% of patients preferred to receive all information about the diagnosis, treatment, and prognosis all at once and up front, whereas 35% preferred to receive it in stages. 75% of patients felt that written information should accompany this. Carers were equally divided with 50% favouring an up front approach, and 50% preferring to receive it in stages. Those favouring an up front approach felt it was necessary for planning, and to manage issues such as driving. 80% of carers felt written information would be helpful.</p> <p>Carers appreciated physicians who provided a sense of hope through explaining how/where to get further treatment and felt that this empowered them.</p>	
McCabe et al., (2019): Patient and companion shared decision making and satisfaction with decisions about starting cholinesterase medication at dementia diagnosis	74 patients 69 companions 21 doctors	UK	Video observations of disclosure meetings and standardised self-report measures	To examine how decisions are made about whether to start cholinesterase inhibitors at diagnosis disclosure meetings	<p>Patients and companions completed the Patient Experience Questionnaire about their disclosure meeting and 59.7% of patients and 35.9% of companions expressed uncertainty on the Outcome scale, 51.5% of patients and 26.8% of companions reported barriers to communication, 53% of patients and 21.7% of companions felt negative or no positive emotion. 4.6% of patients described communication as less than optimal. Overall, patient experience of the disclosure meeting was somewhat negative.</p>	100%
Milby et al., 2017: Diagnosis disclosure in dementia: Understanding the experiences of clinicians and patients who have recently given or received a diagnosis	7 patients 8 clinicians	England	Qualitative interviews with interpretative phenomenological analysis	To explore the lived experience of individuals who have recently given or recently received a diagnosis of dementia	<p>Reactions to receiving a diagnosis described by both patients and clinicians involved shock, fear, and acceptance, but the most common reactions are denial and avoidance. Patients use avoidance to manage their loss of sense of self and anxieties about the future, and clinicians use avoidance by not using explicit terms due to a lack of certainty about the diagnosis, and a desire to minimise distress, as well as respect for patients' wishes not to know the diagnosis.</p> <p>Supportive staff at the MAS put patients at ease and help them to engage with the process. However, a diagnosis delivered without provision of information contributed towards anxiety.</p> <p>Clinicians reported that working with other members of health and social care helped to facilitate post-diagnostic support. Working with other staff also helps to increase confidence in the diagnosis.</p> <p>Clinicians reported that disclosure was draining and that patients' distress does affect them. Being able to share this with a colleague helps to minimise the personal impact.</p> <p>Clinicians felt that a further appointment was needed after disclosure, with the same professional who had disclosed, but heavy caseloads meant that this was often not available.</p>	70%
Moore & Cahill, 2013: Diagnosis and disclosure of dementia – A	9 general practitioners	Ireland and Sweden	Qualitative interviews with thematic analysis	To recognise obstacles to disclosure and explore the extent to which	<p>Only three participants claimed they would normally talk openly about dementia when disclosing the diagnosis; instead six of the GPs tended to explicitly avoid using the word dementia.</p>	70%

comparative study of Irish and Swedish General Practitioners				dementia is considered a stigmatising illness for GPs in Ireland and Sweden		
Mormont et al., 2012: Experiences of the patients and their caregivers regarding the disclosure of the diagnosis of Alzheimer's disease: A Belgian retrospective survey	107 patients and 107 matched caregivers attending a memory clinic over one year	Belgium	Structured interview	To report the experience and agreement/disagreement of patients and caregivers regarding AD diagnosis disclosure	29% of patients declared that they had suffered from the disclosure, but caregivers reported only 15% of patients were still suffering. 85% of caregivers felt the diagnosis had been useful. Patients who could remember their diagnosis significantly more frequently reported that they had suffered compared to those who could not recall, and that they were more anxious. Caregivers of patients who could remember their diagnosis reported significantly more frequently that the patient had suffered, and was still suffering from the disclosure, with a reaction of sadness, depression, anxiety, but also satisfaction to receive an explanation. The disclosure of AD was responsible for anxiety or sadness in approximately one third of patients.	60%
Nielsen et al., 2018: The process of disclosing a diagnosis of dementia and mild cognitive impairment: A national survey of specialist physicians in Denmark	54 specialist physicians (80 invited to participate, response rate 68%)	Denmark	Online questionnaire	To investigate the process and content of diagnostic disclosure meetings in Danish dementia diagnostic services.	98% reported that disclosure is almost always/often performed by a physician and 61% reported that a nurse almost always/often participated in these meetings. 54% never/rarely disclosed on the first encounter. 56% had the opportunity to find out expectations before the meeting, but for 31% this was never/rarely possible. 98% of participants almost always/often discussed pharmacological treatments at the disclosure meeting, and 64% offered follow-up (although 28% never/rarely did so). 95% provided information on psychosocial support. 81% provided written materials to support the verbal information. Patients were encouraged to bring a family caregiver to the disclosure meeting and most participants disclosed to them jointly. 78% of participants regularly used the term AD or dementia of the AD type (52%), or dementia (39%). No respondents used terms senility or age-related impairment. Most respondents shared results from brain scans/assessments and informed on aetiology, progression, causes of symptoms. However, few respondents gave information on prognosis and future symptoms, and the amount of information given was dependent on the degree of cognitive impairment, the specific type of dementia and the level of emotional distress. 100% of respondents discussed issues such as handling medications and 87% discussed driving.	70%
Page et al., 2015: 'Rydym Eisiau Gwybod' the dementia diagnosis disclosure preferences of people in North Wales	253 people with dementia attending memory assessment services	North Wales, UK	Clinical audit	To quantify patients' preferences for diagnostic disclosure	84.1% of patients included in the audit preferred their diagnosis to be disclosed jointly to themselves and a relative or 2.7% to themselves and a third party (a carer). 8.3% of patients preferred to receive their diagnosis alone. All but one of the 4.7% of those	60%

					<p>who did not want to know wanted their diagnosis to be disclosed to a relative.</p> <p>Patients who expressed a preference for non-disclosure were 5.74 times more likely to not have their preferences actioned than those requesting disclosure.</p> <p>Patients requesting joint disclosure were less likely to have their preferences ignored, suggesting the companion represents a reassuring presence not just for the PwD but also the healthcare professional.</p>	
Peel, 2015: Diagnostic communication in the memory clinic: a conversation analytic perspective	15 patients attending memory clinics and 14 accompanying persons	One memory clinic in England	Video recording and conversation analysis of memory clinic appointments	To understand why previous literature labels the disclosure process as difficult, and to generate patient oriented advice on the process	<p>Patients tend not to agree or acknowledge the news delivered by the doctor, even when doctors take an affiliative conversation style by including the patient in the conversation.</p> <p>Bad news tends to be 'shrouded' with positives.</p> <p>Some interactions do not necessarily need the diagnostic labels to be explicit for the diagnosis to be communicated. Unambiguous naming of dementia/AD doesn't always help the patient understand what is happening.</p> <p>Diagnosis is an ongoing, repetitive discussion between healthcare professionals, patients, and carers.</p> <p>Patients themselves tend to normalise their experience, and doctors interact with this, which presents the doctor with a situational dilemma of having a smooth consultation but also not deceiving patients and giving them the opportunity of a timely diagnosis.</p>	80%
Philips et al., 2012: Difficulties in disclosing the diagnosis of dementia: A qualitative study in general practice	21 GPs	Australia	Qualitative interviews	To explore GPs' perceptions of barriers to disclosing the diagnosis of dementia	<p>Disclosure was felt to be difficult if GPs perceived patients to be hiding or denying symptoms of dementia. Disclosure is easier if the patient is already thinking about that diagnosis.</p> <p>GPs in this study reported feeling a sense of trepidation about disclosure as patients were often fearful of the diagnosis. GPs felt that if there was a well-developed doctor patient relationship they should be the one to disclose though, rather than a specialist who may not be known to the patient. However, some participants felt that the specialist could occupy a position of blame, and the GP was then in a position to support their patients. Some GPs felt that disclosure would impact the doctor patient relationship.</p> <p>Family members were felt to be helpful as they usually wanted to know more information, which the GP could focus on, especially if the patient discounted the implications of the diagnosis.</p> <p>Providing education to carers about the patient's behaviour was felt to be important to help them cope with the consequences of the condition.</p> <p>GPs felt it was important to offer hope during the disclosure by confirming peoples' fears and giving them a constructive way to move forwards.</p>	70%

					Some GPs reported using terms such as memory impairment rather than dementia to avoid negative connotations of the word dementia.	
Porteri et al., 2010: Diagnosis disclosure of prodromal Alzheimer Disease – Ethical analysis of two cases	Two patient cases	Europe	Description of two clinical cases	To consider if and how diagnosis should be disclosed in two cases from an ethical perspective	Patients should be given the choice whether to receive the results or not before the assessments take place, and patients should have the chance to change their mind at any point. The authors suggest that a due to the lack of effective treatments, a truthful diagnosis disclosure is not necessary to guarantee the best available treatment in prodromal AD. Disclosure and the terminology used should be based on the patient's current socio-personal context, considering their mood and family support. Biomarkers should be treated with caution as the presence of biomarkers doesn't necessarily translate into the same clinical situation in the future.	100%
Raicher et al., 2008: Alzheimer's disease diagnosis disclosure in Brazil: a survey of specialised physicians' current practice and attitudes	181 Physicians (of a possible sample of 970 potential respondents)	Brazil	Questionnaire	To investigate practices and attitudes of specialised physicians concerning AD diagnosis disclosure in Brazil	85.6% of respondents always used clear terminology such as dementia or AD, and the rest used terms such as memory impairment, forgetfulness, senility, or sclerosis.	60%
Sakai & Carpenter 2011: Linguistic features of power dynamics in triadic dementia diagnostic conversations	86 physician-patient-companion triads	US – Alzheimer's Disease Research Center	Analysis of videotapes of diagnosis disclosure and questionnaires completed by patients and companions	To explore the expressions of power amongst physicians, patients, and companions during disclosure	Physicians dominated the conversations speaking on average for 83% of the time. Patients spoke for 10% of the time and companions spoke for 6% of the time. Companions spoke more when the patient had dementia than when they did not. Patients and companions underestimated the time the physicians spoke, and overestimated their total time talking. Physicians used fewer first person singular pronouns than patients and companions.	95%
Samsi et al., 2014: Negotiating a labyrinth: experiences of assessment and diagnostic journey in cognitive impairment and dementia	27 people with cognitive impairment and 26 carers	Four memory services in UK	Interviews before and after diagnosis disclosure	To understand the experiences, expectations and service needs of people with cognitive impairment and their carer along the service pathway from early awareness to diagnosis disclosure	Many participants in this study felt supported by practitioners at the time and that details of their condition had been explained to them. Some participants described feeling shock, loss, grief, and dejection, and some of these felt that the process of imparting the diagnosis has increased these feelings. Participants wanted to know the long term prognosis, but felt that a staged process of diagnosis disclosure would have helped them to take the news on board, as they had little time to discuss concerns and questions. Carers were keen to talk to the PwD before speaking further to the practitioner because this interaction tended to generate further questions. Participants expressed that they had lacked information, had only been given basic information, and practitioners had disregarded their need to know more.	60%

					<p>Not all types of dementia were supported, for example participants who received a diagnosis of vascular dementia in this study were discharged without support from secondary care because they were not eligible for medication, and reported feeling helpless, shocked, lost and confused.</p> <p>Participants who had been assessed and diagnosed in their own homes reported a positive experience, whereas some participants visiting clinics did not.</p>	
Segers, 2009: What Belgian geriatricians tell their patients with Alzheimer's disease and why: a national survey	88 geriatricians (72 valid responses; 28.5% response rate of an initial 309 approached)	Belgium	Questionnaire using open and multiple choice questions	To understand geriatricians' attitudes towards disclosure of AD, and whether these opinions differ from those of neurologists and neuropsychiatrists.	<p>Participants preferred to use the term memory disease (59%) over AD (48%) with PwD, but preferred to use AD with relatives (87%).</p> <p>More than 55% of participants ask the PwD if they want to know their diagnosis, but only 39% ask the PwD if they can reveal it to their family. 18% asked the family if they should reveal the diagnosis to the PwD.</p> <p>71% of participants provided information about the prognosis and progression of AD to the PwD and 94% did to the family. Most cited reasons for not informing PwD of this was that they did not ask (94%), or the participant was fearful of a depressive reaction (71%), or that the knowledge was useless to the PwD (29%)</p> <p>The most frequent emotional reactions of PwD on hearing the diagnosis were depressive reaction (50%), indifference (51%), anxiety/nervousness (46.8%) and denial/minimisation (40%). The most frequent emotional reaction from family members was anxiety (50%).</p>	80%
Shimizu et al., 2008: Disclosure of the diagnosis of Alzheimer's disease	50 carers of PwD and 50 control participants who were not carers	Brazil	Structure questionnaire interview	To investigate the opinion of a Brazilian sample of participants on the disclosure of an AD diagnosis	<p>90% of carers would want the diagnosis disclosed to them if they had AD, and 98% of the controls expressed this wish.</p> <p>52% of carers and 57% of controls felt that it was the PwD's right to know, and ranked this the top justification for disclosure.</p>	80%
Stokes et al., 2014: Understanding the dementia diagnosis: The impact on the caregiving experience	10 spousal carers of PwD recruited from local dementia groups and care homes	The midlands, England	Semi-structured interviews using IPA	To understand how caring partners make sense of the diagnosis and how it impacts their experiences as caregivers.	<p>Participants wondered why professionals had not been more forthcoming with information and wondered if this was deliberate or accidental. Carers expressed a wish for information about typical manifestations of dementia and practical information about health, social, and financial support.</p> <p>Some carers were able to use the medical explanation provided as a framework to explain the PwD's behaviour and changes. Others found the medical framework incomplete for understanding the condition, and this seemed to occur when there was a lack of explanation of the condition.</p>	100%
Van-Wijngaarden et al., 2018: Entangled in uncertainty: The experience of living with dementia from the	57 carers of people with dementia recruited through research advertisements	The Netherlands	47 semi-structured interviews and two focus groups (N=6 and 4)	To develop an insight into what it means to live with dementia from the perspective of family members	<p>For most participants disclosure of the dementia diagnosis was paradoxical in that it provided relief and an explanation of the behaviours their loved one had displayed, but left carers in a state of uncertainty, with no idea about the course of the disease or expectations for the future.</p>	80%

perspective of family caregivers					Carers receive a new role at the disclosure of the diagnosis, in an instant they go from not being a carer to being a carer, but without any education as to what this new role involves. Many respondents were annoyed at the lack of information. Disclosure took away hope and trust in the future for some participants as they associated dementia with a humiliating, progressive process involving poor care and social exclusion. A small minority of carers preferred to receive the disclosure themselves and not tell the PwD.	
Villars et al., 2010: The primary care physician and AD: An international position paper			Group opinion of a panel of expert neurologists, geriatricians, and family medicine experts from developed countries	To establish the role of the primary care physician in detection, early diagnosis, treatment and follow up, and in clinical trials of dementia	The disclosure protocol should be a repeated and planned announcement where the diagnosis is disclosed by the specialist, and again by the PCP to reaffirm. PCPs need training opportunities to integrate this disclosure into their consultation. Disclosure must occur before care planning, and provide basic education to the family. Care plans should be presented to avoid causing excessive concern to PwD and families about the progression of dementia. Legal issues such as advance directives, designated people of trust and driving can be covered at this time.	100%
Vince et al., 2017: The meaning and experience of well-being in dementia for psychiatrists involved in diagnostic disclosure: a qualitative study	11 Psychiatrists	Three NHS Trusts in North of England	Semi-structured interviews with IPA	To explore the meaning of living well with dementia from the perspective of psychiatrists and their subjective experiences of discussing well-being during diagnostic disclosure	Participants' understanding of well-being was underpinned by a nihilistic and reductionist view of dementia, embedded within the medical model that dementia represents a threat to well-being directly associated with a decline in functioning. Diagnostic disclosure meeting viewed as a key event in a person's life and an opportunity to discuss well-being and engagement with services, although some participants felt the shocking nature of the disclosure meant that well-being should be addressed at a later time point. Disclosure is only helpful in supporting well-being if people are ready to hear their diagnosis, and that early diagnosis can be detrimental to well-being. Participants felt that it was right to tailor language even though this raised dilemmas for whether to disclose the diagnosis in full and explicit terms. Participants expressed tensions between positivity and reality, as they wanted to provide positive messages that were genuine and realistic about the future. Participants felt that the diagnosis was a separate part of the discussion to well-being. Participants described a discrepancy between the care they wished to provide and the care they did provide, for example the practical and emotional difficulties of disclosing a diagnosis to someone with whom they do not have a therapeutic relationship.	90%
Visser et al., 2012: Disclosure of Alzheimer's disease biomarker status			Opinion/commentary	Comment on the interpretation of biomarker scores in	The authors propose the shared decision making model. Physicians should provide information on possible outcomes before biomarker testing, and agree with patients whether they	100%

in subjects with mild cognitive impairment				people with MCI and present an approach to disclose them	want to undertake testing and know the results. The implications of different outcomes should be fully explained at disclosure.	
Woods et al., 2018: Timely diagnosis of dementia? Family carers' experiences in 5 European countries	1409 carers	Czech Republic, Finland, Italy, the Netherlands, & Scotland	Survey of informal carers' views	To examine the carers' experience of the diagnostic process, disclosure of diagnosis, and impact of diagnosis over time.	47% of carers felt the diagnosis was delayed, and contributing factors were the PwD refusing to be assessed (38%) and negative professional attitudes (33%) where the first professional seen did not consider anything wrong and being told there was no point in a diagnosis (7%). Carer ratings of quality indicators of sharing the diagnosis were generally favourable, except for pre-diagnostic counselling (did PwD want to know?), for the carer being able to speak to the healthcare professional alone, and for having a written summary. Higher quality diagnosis sharing was associated with lower sadness, depression, and despair, and greater acceptance, reassurance both immediately after diagnosis, and beyond (average of 4 years).	100%
Wynn et al., 2017: Discourse features among providers, patients, and companions, and their effect on outcomes of dementia diagnosis disclosure	84 PwD/companion dyads 7 physicians	USA Memory and Aging Project study at Washington University	Videos of diagnostic feedback sessions and follow-up telephone interviews	Quantify the content of diagnostic conversations to examine the prevalence of different types of discourse across stakeholders. Investigate relationship between elements of discourse to dementia severity and psychological outcomes.	With increasing dementia severity patients spoke less in the interaction. Providers (Healthcare professionals) spoke most frequently, accounting for an average of 73% of the dialogue. Patients used Lifestyle/Psychosocial Information and Emotional Rapport building features of dialogue more than companions. Providers and companions gave more medical/Therapeutic information as dementia severity increased. More positive rapport building from providers was associated with lower depression and anxiety scores for PwD.	90%
Xanthopoulou, et al., 2019: Patient and companion concerns when receiving a dementia diagnosis: an observational study of dementia diagnosis feedback meetings	19 healthcare professionals 60 patients 59 companions	UK	Video observations of disclosure meetings	This study explored concerns expressed in HCP–patient–companion communication in specialist memory clinics during the dementia diagnostic feedback meeting.	Topics of concern for patients and companions included the dementia diagnosis itself, symptoms of dementia, impact on family, physical health of the patient, frustration with the symptoms of dementia, mental health, medication, prognosis, the role of the companion, lack of social connection and other. All concerns were given a response by the healthcare professional, where 62% were encouraged to elaborate and 38% were discouraged from elaborating. When concerns were elicited by the healthcare professional, they were more likely to respond by encouraging elaboration, but comparatively when concerns were volunteered by the patient or companion the healthcare professional was more likely to respond by discouraging elaboration.	100%
Zaleta et al., 2010: Patient-centred communication during the disclosure of a dementia diagnosis	54 PwD-companion-physician triads (10 physicians)	USA Memory and Aging Project study at Washington University	Videos of interactions coded with Roter Interaction Analysis System. Coders concentrated on 15 patient-centred	Characterise the extent to which physicians adopt a patient-centred approach in disclosure. Evaluate whether patient-centred behaviours differ in	The most frequent patient-centred behaviour was positive rapport building, in particular physician agreement with PwD/companion and showing approval. Facilitation and patient activation was the next most frequent category of behaviours, with back channelling most commonly used (signalling interest with non-lexical utterances), followed by checking their understanding, and the PwD/companion's understanding.	80%

			physician behaviours and looked for expressions of positive affect.	relation to patient characteristics.	Physicians asked for PwD/companion opinions, permission, or reassurance less frequently. Emotional rapport building was the least used category of behaviours and occurred infrequently. Physicians rarely offered statements of reassurance or optimism, and infrequently expressed concern or worry. Few instances of empathy were demonstrated, PwD/companion feelings were infrequently legitimised and physicians tended not to self-disclose or create a sense of partnership with the PwD/companion. There was considerable variation between physicians, but physicians were generally consistent in their behaviours within themselves.	
Zaleta et al., 2012: Agreement about diagnosis among patients, companions, and professionals following a dementia evaluation	90 PwD and companion dyads	USA Memory and Aging Project study at Washington University	Video of diagnostic disclosure Diagnostic impressions collected from physician, PwD, companion, written summary from nurse present at disclosure, & trained raters viewing the video. PwD & companions contacted separately by phone and asked structured interview.	Provide a systematic evaluation of agreement among physicians, PwD, companions, and other professionals about results of diagnostic work-up.	Consensus was moderate but far from perfect, and generally PwD had only fair agreement with other sources. PwD and companions felt feedback was thorough, suggesting self-perceived comprehension was high Physicians felt that PwD who agreed with the disclosure understood the feedback better than those who did not agree. PwD tended to report no dementia when other sources believed they had dementia.	80%
Zou et al., 2017: Caregivers' attitude toward disclosure of Alzheimer's disease diagnosis in Urban China	164 carers of patients attending memory outpatients clinic	Urban China	Questionnaire study of carers of PwD	Obtain the attitude of carers towards disclosure of AD to patients	For carers of PwD who knew the diagnosis, half felt the PwD had suffered emotionally from knowing. 95.7% of carers would want to know themselves if they had dementia. 97.6% of carers would want the diagnosis disclosed to a family member if they had dementia. Reasons for disclosure included having a right to know, slowing the disease, facing the condition positively, know what is happening to them, and plan for the future.	100%

AD: Alzheimer's disease, GP: General Practitioner, MAS: Memory Assessment Service, OAMHTs: Older Adult Mental Health Teams, PwD: People with dementia

Figure 1: PRISMA flow diagram of included studies

